Abstract

Background

As people with intellectual disabilities (ID) are now living longer, they are more at risk of developing non-communicable diseases, including type 2 diabetes mellitus (T2DM). However, understanding of factors associated with diabetes for targeted management and prevention strategies is limited. This study aimed to investigate prevalence of diabetes in adults (aged ≥ 18 years) with ID and its relationship with demographic, lifestyle, independence or health factors.

Method

This was a cross-sectional analysis of interview data from 1,091 adults with ID from the Leicestershire Learning Disability Register from 1 January 2010 to 31 December 2016. Logistic regression models were used to identify factors associated with diabetes in the study population.

Results

The study population did not have healthy lifestyles: just under half reported having lower physical activity levels than people without intellectual disabilities of a similar age; one-quarter consumed fizzy drinks daily; and 20% consumed 5 or more fruit and/or vegetables per day. Prevalence of carer/self-reported diabetes was 7.3% (95% CI 5.9–9.0). After adjustment, diabetes was positively associated with South Asian ethnicity ($p=0.03$) and older age groups ($p<0.001$). Diabetes was less common

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in people living with family members ($p=0.02$). We did not find a relationship between any of the lifestyle, independence and health factors investigated.

Conclusions

A significant proportion of people with ID are living with diabetes. Diabetes management and prevention strategies should be tailored to individuals' complex needs and include consideration of lifestyle choices. Such strategies may want to focus on adults of South Asian ethnicity and people living in residential homes where prevalence appears to be higher.

Keywords

Intellectual disabilities

Diabetes

Lifestyle

Independence

Health

Introduction

As the life expectancy of people with intellectual disabilities (ID) increases (World Health Organisation 2000, Emerson *et al.* 2012, Bittles *et al.* 2002, Dieckmann *et al.* 2015), they become more at risk of developing later non-communicable diseases, including type 2 diabetes mellitus (T2DM) (Cooper *et al.* 2018, Hermans and Evenhuis 2014, Reppermund & Trollor 2016). In theory, prevention strategies should focus on reducing the burden of T2DM but this can be challenging because of the complex interplay between physical and mental health problems, and support needs that contribute towards health inequalities in this population (Kinnear *et al.* 2018, Schutzwahl *et al.* 2016). Preventing or delaying the onset of T2DM is important because T2DM is a progressive disease that is associated with a range of microvascular and macrovascular complications, including peripheral neuropathy, chronic kidney disease, coronary artery disease, heart failure and stroke (Kosiborod *et al.* 2018). For people with ID who are already living with T2DM, diabetes management can be variable (Taggart *et al.* 2013; Shireman *et al.* 2010) but evidence suggests that, with the right support, they can be effectively involved in their own care (House *et al.* 2018).

Diet and physical activity are known to be key modifiable risk factors that should be integrated into lifestyle interventions to prevent or delay the onset of T2DM (American Diabetes Association 2017, Diabetes Australia Guideline Development

Consortium 2009, Paulweber *et al.* 2010). Compared with the general population, people with ID are more likely to have unhealthier diets (Robertson *et al.* 2000, Hoey *et al.* 2017), exercise less (Bartlo and Klein 2011, Dairo *et al.* 2016) and lead more sedentary lifestyles (Melville *et al.* 2018, Haveman *et al.* 2011). They are also more likely to have complex physical health and/or mental health problems (Cooper *et al.* 2015, Hughes-McCormack *et al.* 2017) which further decreases their likelihood of leading healthy lifestyles (Harris *et al.* 2018, Tyrer *et al.* 2019).

The evidence base for associated factors and prevention strategies for diabetes in the general population is very robust but the research is limited in the ID population. In order to target people with ID who could benefit from diabetes management programmes and prevention, it is important to quantify the extent of the problem and to identify factors associated with diabetes so that prevention and management can be tailored to their complex needs. Therefore, the aims of this study were to estimate prevalence of diabetes and its relationship with demographic, lifestyle, independence and health factors, in a representative population of adults with ID.

Method

Design

This was a secondary analysis of data from the Leicestershire Learning Disability Register. The register is described in detail elsewhere (McGrother *et al.* 1996,

Watson 2003). Briefly, it is a cohort of all adults (aged ≥ 18 years) attending specialist ID health and social care services in Leicestershire covering the geographical locations of Leicester city, Leicestershire and Rutland between June 1986 to December 2016. Before its closure in March 2017, the register operated a rolling programme of interviews with carers (informal carers, usually parents in family homes and formal paid carers in residential/supported accommodation) and/or adults with ID (if they were able). Interviews were carried out by allied health professionals employed at Leicestershire Partnership NHS Trust using a semi-structured questionnaire that incorporated questions from the Disability Assessment Schedule (DAS) (Holmes *et al.* 1982). All questions used in this analysis were categorical, requiring only one response from multiple categories, unless otherwise specified. Uptake for interviews was 90%. For the purposes of this study, we excluded adults who were using specialist ID services but were defined as “no ID” (e.g. acquired brain injury in adulthood). The most recent interview on or after 1 January 2010 to 31 December 2016 was included.

Outcome measure

Diabetes was a carer/self-reported question collected during the home interview from the carer and/or individual: “Has a doctor ever told you that s/he has [you have] diabetes?” Possible responses were “yes”, “no” or “unsure”.

Covariates

Demographic factors

Demographic factors age, gender and ethnicity (defined from UK census categories and grouped into White, South Asian, other) were selected based on their conceptual relationship with diabetes in the general population and ID literature (Gray *et al.* 2010, MacRae *et al.* 2015). We also included type of accommodation (living independently [including spouse], with family and residential accommodation).

Pre-existing genetic conditions

We included presence/absence of Down syndrome, as reported by the carer/individual; this was the only genetic condition routinely collected at interview.

Ability, independence and lifestyle factors

Independence/lifestyle questions were included on level of understanding (a proxy for severity of ID), independence measures (degree of supervision, feeding, food preparation), physical activity (physical activity levels, participation in sports), diet (fruit/vegetable consumption, fizzy drinks) and smoking status.

Physical health

Physical health questions comprised perception of physical health, mobility status, sight and hearing. For the sensitivity analysis (see Analyses), we also included body mass index (BMI; calculated from reported height and weight). BMI categories were

divided into four categories (Underweight: BMI < 18.5 kg/m²; Normal: BMI ≥ 18.5—< 25 kg/m²; Overweight: BMI 25 —< 30 kg/m²; Obese: BMI ≥ 30 kg/m²; and Not known). For South Asian individuals, we used the lower BMI thresholds (23 kg/m² for overweight and 27.5 for obesity) as recommended in UK and international guidance (National Institute for Health and Care Excellence 2012, WHO Expert Consultation 2004).

Challenging behaviours

Aggressive challenging behaviour (from the DAS) was defined as physical aggression, self-injury, aggression towards objects (destructive behaviour, throwing objects around) and/or verbal aggression that was severe and/or frequent (≥ 3 times/wk).

Analyses

The characteristics of the study population were described. The relationships between diabetes, demographic factors, lifestyle, independence and health factors were explored using single-variable logistic regression models. Factors significant at the 5% level were incorporated in a multiple logistic regression model. Analyses were carried out in Stata version 14 (Statacorp 2015). To control for the established relationship between BMI and T2DM (Gray et al. 2010, MacRae et al. 2015), a sensitivity analysis was also conducted by adding BMI category to the adjusted model, recognising that this variable was often missing.

3. Results

Study population

Table 1 shows the characteristics of the 1091 individuals who were interviewed between 1 January 2010 and 31 December 2016 and had information on diabetes status available (16 individuals were removed who had “unknown” status). The population was generally young, with more than half of individuals (57%) in the 20–29 year age group (mean age 33.2 year; range 18–80 years). The majority (58%) of individuals were male, white (82%) and most (54%) lived in family homes, usually with parents (82% of those living in family homes). Down syndrome was reported in 13% of the population. The study population did not typically have healthy lifestyles: just under half were perceived by carers/individuals to have lower physical activity levels than other people of the same age, one-quarter consumed fizzy drinks daily and only 20% had 5 or more fruit and/or vegetables per day. The presence of challenging behaviours was high, with 35% meeting the criteria for aggressive challenging behaviours.

[Table 1 about here]

Prevalence of carer/self-reported diabetes and associated factors

Prevalence of diabetes and associated factors are also shown in Table 1. The prevalence of carer/self-reported diabetes was 7.3% (95% CI 5.9–9.0) and was higher in females than males.

There was a reduced odds of having diabetes among those living with family compared with residential homes. Older age group categories had higher odds of reported diabetes compared with the 20–29 year age range. Ethnicity and gender were not associated with diabetes but we chose to retain these in the multivariable model as they had been considered a priori as demographic factors that could potentially influence the outcome. We did not find a relationship between diabetes and Down syndrome nor any of the ability, independence, lifestyle, physical health or behaviour measures under investigation.

In the adjusted model to explore the independent contributions of gender, age group, ethnicity and type of accommodation (Figure 1), we found that people with prevalent diabetes (carer/self-reported) were more likely to be older ($p<0.001$) and of South Asian ethnicity ($p=0.03$). Conversely, carer/self-reported diabetes was lower among people with ID who were living at home with their families ($p=0.02$).

[Figure 1 about here]

In the sensitivity analysis, we found that a substantial proportion of individuals had missing BMI status ($n = 466$; 43%). On adding BMI to the model, the relationship between diabetes and age group ($p < 0.001$ for both), South Asian ethnicity (OR=2.26; 95% CI 1.10–4.62; $p = 0.03$) and living with family (OR=0.49; 95% CI 0.26–0.93) remained. There was also an effect of obesity on diabetes (OR=2.46; 95% CI 1.14–5.30 compared with normal weight) but this must be interpreted with caution, given the abundance of missing data.

Discussion

In this population-based study of adults with ID living in Leicestershire, UK, we found that carer/self-reported diabetes of any type was associated with older age and South Asian ethnicity. Diabetes was also less prevalent in adults with ID who were living in family households. We did not find any evidence of a relationship between diabetes and the potentially modifiable lifestyle, independence and health factors that we investigated.

The prevalence of diabetes in this adult population was 7.3%, which is lower than previous estimates and unadjusted European general population figures of around 9% (Dunkley *et al.* 2017b, International Diabetes Federation 2017). This is likely to reflect the younger age distribution in our study cohort as compared with the general population (i.e. only 17% in our cohort were aged 50 years or over). Age-adjusted

prevalence is typically higher among people with ID because they tend to follow a younger age distribution (Flygare Wallen *et al.* 2018), with older individuals disproportionately affected by diabetes (Axmon *et al.* 2017). Nonetheless, our findings reveal a substantial proportion of adults with ID living with diabetes. Whilst self-management education and support are core components of diabetes and glucose control (Davies *et al.* 2018), they must be seen in the context of ID. As well as inherent intellectual and adaptive behaviour impairments, people with ID and diabetes are disadvantaged in terms of additional comorbidities (House *et al.* 2018), choice of glucose-lowering therapies (Axmon *et al.* 2017) and quality of care (Taggart *et al.* 2013; Shireman *et al.* 2010). It is vital that specially tailored management plans with multidisciplinary input from healthcare professionals are in place to meet their needs.

Our finding with regard to family households is interesting but must be interpreted with caution owing to its likely bi-directional relationship with diabetes. It is possible that family carers are more effective at enforcing healthy lifestyle behaviours, given that residential carers are not able to provide the same level of one-to-one tailored support or to develop such close relationships with their clients. Residential carers may also encounter organisational barriers to enforcing healthy lifestyle behaviours (O’Leary *et al.* 2018). However, it is equally possible that individual-level factors associated with lifestyle, such as knowledge about diabetes, severity of ID and multimorbidity (Caton *et al.* 2012; Melville *et al.* 2018; Tyrer *et al.* 2019), differ by

accommodation status. Prior research suggests a selection mechanism whereby healthy adults (as opposed to less healthy) adults with ID are less likely to be moved from family homes to residential accommodation (Woodman *et al.* 2014) which would suggest that people with diabetes are more likely to transfer to residential settings. Finally, our findings may reflect a lack of testing for diabetes in family households. Anecdotal evidence from our own screening study of T2DM in adults with ID (Dunkley *et al.* 2017a) suggests that family carers could be reluctant to consent to a blood test, whereas such measurements were often routinely collected in residential settings. We recommend further research in this area.

A novel finding in our study was the increased odds of reported diabetes among South Asian communities with ID. This finding was not observed in the single-variable analysis because substantially more people of South Asian descent were living with family members (83% vs 49% and 58% for white and other ethnic groups). The increased risk of T2DM in the South Asian community has been largely overlooked in the ID literature but is well established in the general population (Holman *et al.* 2011, Fischbacher *et al.* 2009). A number of reasons have been put forward for this increased risk, including a more centralised distribution of body fat in South Asian communities, meaning that lower BMI and waist circumference confer greater risk profiles than the rest of the population (Razak *et al.* 2007, Gray *et al.* 2011). Cultural barriers to healthy lifestyle changes have also been proposed (Patel *et al.* 2017). We are unable to explore these explanatory pathways in more depth in

this retrospective data analysis and recommend further work on the influential factors that contribute to diabetes among South Asian communities with ID.

Limitations

A key limitation of our study was that our outcome measure and covariates were self-reported by carers/individuals with ID. Our study also relied on adults having been given a previous diagnosis; undiagnosed diabetes has been found to be relatively low in the study location but could only be determined on those who consented to be tested (Dunkley et al. 2017a). It was also not possible to distinguish between type 1 diabetes mellitus, which is not lifestyle-related, and T2DM. However, T2DM represents approximately 90% of all diabetes (NICE, 2015).

Conclusions

Our study findings highlight the need for strategies that are tailored to the needs of people with ID for both prevention and management of diabetes. Prevention strategies should consider high-risk groups including those of South Asian ethnicity. Management for those living with diabetes should include ID health professionals to meet their complex needs and may be particularly important for those living in residential settings. Given the high prevalence of unhealthy lifestyles in our study, we think it is particularly important to focus on changing risk factors for T2DM by promoting healthy eating and physical activity in people with ID.

Conflict of interest

The authors declare that there are no conflicts of interest.

Figures and Tables

Table 1: Single variable analysis for covariates associated with diabetes

Characteristic	Total (N=1091)		Diabetes (N=81)		Relationship between covariate and diabetes		
	N	%	N	(%)	OR	95% CI	p-value
Demographic Characteristics							
Age group at interview (years)							
18 – 29	621	(56.9)	11	(13.6)	1.00	(ref)	-
30 – 49	282	(25.9)	34	(42.0)	7.60	3.79 – 15.24	<0.001
50+	188	(17.2)	36	(44.4)	13.13	6.53 – 26.40	<0.001
Gender							
Male	636	(58.3)	44	(54.3)	1.00	(ref)	
Female	455	(41.7)	37	(45.7)	1.19	0.76 – 1.88	0.45

Ethnicity							
White	897	(82.2)	65	(80.3)	1.00	(ref)	-
South Asian	139	(12.7)	13	(16.1)	1.32	0.71 – 2.47	0.38
Other/Unknown	55	(5.0)	3	(3.7)	0.74	0.22 – 2.43	0.62
Type of accommodation							
Living independently	133	(12.2)	11	(25.9)	0.54	0.26 – 1.14	0.11
Living with family	584	(53.5)	21	(25.9)	0.24	0.14 – 0.40	<0.001
Residential care	344	(30.8)	47	(58.0)	1.00	(ref)	-
Not recorded	30	(3.5)	2	(2.5)	0.55	0.16 – 1.85	0.331
Pre-existing genetic conditions							
Down syndrome present	144	(13.2)	8	(9.9)	0.70	0.33 – 1.49	0.34
Ability, independence and lifestyle factors							
Level of understanding (n=1089)							

Little/nothing	151	(13.9)	6	(7.4)	0.42	0.17 – 1.03	0.06
Practical/personal needs only	533	(48.9)	39	(48.2)	0.81	0.50 – 1.30	0.38
Can make limited/informed decisions	405	(37.2)	36	(44.4)	1.00	(ref)	-
Degree of supervision (n=1090)							
No/minimal supervision	164	(15.1)	70	(86.4)	0.88	0.46 – 1.70	0.70
Regular/constant supervision	926	(85.0)	11	(13.6)	1.00	(ref)	-
Ability to feed him/herself (n=1090)							
Not at all	80	(7.3)	3	(3.8)	0.44	0.14 – 1.46	0.18
With help/supervision	378	(34.7)	26	(32.5)	0.84	0.52 – 1.37	0.49
Without help	632	(58.0)	51	(63.8)	1.00	(ref)	-
Ability to prepare food							
Needs all food prepared	337	(30.9)	21	(25.9)	0.74	0.44 – 1.24	0.26
With help/simple foods	692	(63.4)	57	(70.4)	1.00	(ref)	-

Variety of foods	62	(5.7)	3	(3.7)	0.57	0.17 – 1.86	0.35
Physical activity levels compared with other people of a similar age (n=1067)							
Less	489	(45.8)	32	(40.5)	1.00	(ref)	-
About the same	437	(41.0)	36	(45.6)	1.28	0.78 – 2.10	0.33
More	141	(13.2)	11	(13.9)	1.21	0.59 – 2.46	0.60
Participates in sports							
Not at all	805	(73.8)	65	(80.3)	1.00	(ref)	-
Occasionally/Regularly	288	(25.9)	16	(19.8)	0.67	0.38 – 1.19	0.16
Fizzy drinks consumed (n=1021)							
Daily	251	(24.6)	19	(24.7)	0.98	0.55 – 1.75	0.98
Weekly	288	(28.2)	21	(27.3)	0.95	0.54 – 1.65	0.95
Less often	482	(47.2)	37	(48.1)	1.00	(ref)	-

Fruit/vegetable portions per week (n=595)							
<5	472	(80.4)	30	(79.0)	1.00	(ref)	-
≥5	115	(19.6)	8	(21.1)	1.10	0.49 – 2.47	0.82
Smoking status (n=1072)							
Non-smoker	977	(91.1)	68	(89.4)	1.00	(ref)	-
Current smoker	95	(10.5)	8	(10.5)	1.23	0.57 – 2.64	0.60
Physical health							
Perception of physical health (n=1085)							
Good/Excellent	825	(76.0)	55	(10.0)	1.00	(ref)	-
Moderate/Fair	195	(18.0)	17	(21.3)	1.34	0.76 – 2.36	0.32
Poor	65	(6.0)	8	(68.8)	1.96	0.89 – 4.32	0.09
Mobility (ability to walk; n=1090)							
Normal	812	(74.5)	63	(77.8)	1.00	(ref)	-

Restricted/aided	175	(16.1)	13	(16.1)	0.95	0.51 – 1.77	0.88
Non-mobile	103	(9.5)	5	(6.2)	0.61	0.24 – 1.54	0.29
Visual status (n=1078)							
Normal sight	941	(87.3)	60	(87.3)	1.00	(ref)	-
Sight impaired	137	(12.7)	10	(12.7)	1.00	0.50 – 1.98	0.98
Hearing status (n=1078)							
Normal hearing	1002	(93.0)	75	(94.9)	1.00	(ref)	-
Hearing impaired	76	(7.1)	4	(5.1)	0.69	0.24 – 1.93	0.48
Challenging behaviours (severe and/or frequent)							
Aggressive challenging behaviours (n=1097)	377	(35.1)	28	(34.6)	0.98	0.61 – 1.57	0.92
<i>Aggression towards others</i>	219	(20.2)	16	(19.8)			
<i>Aggression towards objects</i>	172	(15.9)	11	(13.6)			
<i>Self-injury</i>	138	(12.8)	9	(11.1)			

<i>Verbal aggression</i>	224	(20.7)	18	(22.2)			

OR Odds ratio; CI confidence interval

Figure 1: Factors associated with diabetes among adults with intellectual disabilities (multivariable model*)

* adjusted for all other factors listed (i.e. gender, age group, ethnicity and accommodation)

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